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ABSTRACT

There are many factors behind the growing advocacy movement for mentally ill individuals. These factors include the prevalence of mental illness in society, deinstitutionalization, the restrictions of managed care, an increased awareness of the rights of the mentally ill, and empowerment of mentally ill clients. Despite the growing importance of advocacy groups, information regarding who they are, what they do, and how to access them is not readily available. This paper is designed to provide counselors with this information. The wide range of service provided by advocacy groups is presented. A list is provided that can be utilized as a quick reference to some of the largest advocacy groups currently in existence. The history of each group and contact information are included. A list of organizations that can provide information on other groups, internet resources, and two useful directories are also included. (MKA)

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Chapter Fourteen

Working with Mental Health Advocacy Groups

Megan Tenety & Mark Kiselica

With the downsizing of state-run psychiatric institutions and better psychotropic medication, an increasing number of mentally ill persons are returning to the community. At the same time, limited community resources and constraints imposed by managed care organizations are limiting the quality and quantity of services provided to the mentally ill. Therefore, counselors must develop creative strategies for meeting the needs of their mentally ill clients. This theme paper describes how counselors can access and use advocacy groups, whose services are typically provided free of charge, to assist their mentally ill clients.

Advocacy groups are a diverse collection of organizations, people, and agendas. Although many advocacy groups join together to work in coalitions or meet common goals, they do not always act as a united front. The agendas and tactics of groups vary as do the members, attenders, and the issues they serve. Some advocacy groups have substantial political respect, while others are considered more radical, taking extreme stances on issues such as opposition to psychiatry or the nature of mental illnesses.

The make-up of organizations also varies. Some organizations are run by "consumers" (i.e., individuals who utilize the mental health system) who may be supportive of the mental health system. Other organizations are run by individuals who call themselves "psychiatric survivors." Generally, psychiatric survivors reject the system and oppose forced treatment laws and the use of psychotropic medications. Some organizations are solely run by the individuals they serve, some mandate a ratio of consumers and non-consumers, and others do not include consumers. Different organizations often represent the interest of contrasting parties in the mental health care debate—psychiatrists, consumers, families, civil libertarians, politicians, managed care providers,

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and psychologists.

The diversity within advocacy groups has caused some debate and conflict among them. According to Paul R. Benson in a 1992 article in the International Journal of Law and Psychiatry, the discrepancy between various groups serves to weaken the possible impact advocacy groups could have in the political arena. Despite this, the presence of advocacy groups is believed to be a major force behind the improved services offered to the mentally ill.

Rationale

There are many factors behind the growing advocacy movement for mentally ill individuals. These factors include the prevalence of mental illness in society, deinstitutionalization, the restrictions of managed care, an increased awareness of the rights of the mentally ill, and empowerment of mentally ill clients. Despite the growing importance of advocacy groups, information regarding who they are, what they do, and how to access them is not readily available. This article is designed to provide counselors with this information.

Strategies

Advocacy groups provide a wide range of services for consumers, family members, and professionals. In addition to offering direct services and support groups, advocacy groups work to:

- Enhance the rights of persons diagnosed with mental illnesses
- Educate consumers, the public, and professionals
- Maintain toll-free hotlines and act as referral sources
- Lobby state and federal governments on behalf of the mentally ill
- Assess the level of care offered by mental health facilities
- Empower consumers
- Advocate for increased research funding
- Facilitate workshops and annual conferences
- Advocate for improved community resources (housing, job training, etc.)
- Decrease the stigmatization of mental illness
- Defend the civil rights of people with mental illnesses
- Offer support groups for the mentally ill and their families

Advocacy groups provide counselors with a powerful and valuable resource. Counselors can access advocacy groups to locate other resources and information or to gain the support of a larger voice in an effort to advocate for a client. Counselors can enhance the range of services offered to clients and their families by linking them with advocacy groups. Through advocacy groups, clients and their family members can share experiences, information, and support with others in similar situations, thereby connecting them with a larger community and decreasing their feelings of isolation and stigmatization. Advocacy groups are a service that clients can use themselves to feel empowered, to learn more about issues that affect them, and to have a say on such issues.

Suggested Resources

Today, there are hundreds of advocacy groups working to improve the lives of the mentally ill. The following list is provided as a quick reference to some of the largest advocacy groups currently in existence.

National Mental Health Association (NMHA). Founded in 1909 by Clifford Beers under its original name, The American Foundation for Mental Hygiene, NMHA is a mental health consumer advocacy organization devoted to fighting mental illnesses and promoting mental health. NMHA advocates for increased research funding, supports community mental health center programs, and assesses the level of care in residential facilities. This organization also works to promote the growth of consumer self-help groups. NMHA lobbies for more humane treatment of the mentally ill and for expanded services in the community. This organization was a major force behind the Mental Health Act of 1946 and the Community Mental Health Centers Act of 1963. NMHA serves as a national resource for educational materials, conducts public education, and works to increase public action through the media.

NMHA can be contacted at: NMHA 1021 Prince Street, Alexandria, VA 22314-2971, Phone: 703.684.7722, 800.969.NMHA, Web: www.nmha.org.

National Alliance for the Mentally Ill (NAMI). Founded in 1979, NAMI was created to address the host of problems resulting from the deinstitutionalization movement. NAMI began when a number of local self-help groups for families of the mentally ill discovered each other's existence and joined together. NAMI has become a nationwide network of local and state affiliates. NAMI offers a variety of services for persons with mental illnesses and their

families, such as self-help programs, public awareness, encouraging cooperative dialogue between service providers, direct services to consumers, response to families in pain, and pursuit of increased research funding. NAMI targets outreach efforts for special groups, such as mental health consumers, minorities, siblings of mentally ill persons, families affected by a member's mental illness, families of mentally ill chemical abusers, and families caught in the criminal justice system. NAMI is a consumer organization that works in coalition with professional and provider organizations.

NAMI can be contacted at: NAMI, 200 N. Glebe Road, Suite 1015, Arlington, VA 22203-3754, Phone: 703.524.7600, 800.950.NAMI, TDD: 703.516.7991, Web: www.nami.org.

National Empowerment Center (NEC). The NEC is a consumer-run organization that works to carry a message of recovery, empowerment, hope, and healing to people with mental illnesses. The NEC offers a national directory of mutual support groups, drop-in centers and state-wide organizations, networking and coalition building, a collection of free or low priced materials, education and training to providers from a consumer/survivor perspective, and a database with hundreds of topics of interest.

NEC can be contacted at: NEC, 20 Ballard Road, Lawrence, MA 01843-1018, Phone: 800.769.3728, Web: www.power2u.org.

Bazelon Center for Mental Health Law. Formerly know as the Mental Health Law Project, Bazelon is a non-profit public interest group concerned with promoting the civil rights of people with mental illnesses and developmental disabilities. The Bazelon Center advocates for mental health policies at the federal and state levels; monitors issues; provides technical assistance; advocates for the Supplemental Security Income program, protection, and advocacy groups; outreach programs; and programs serving infants and children. The Bazelon Center is a partnership of lawyers, policy advocates, mental health experts, and mental health consumers. Bazelon Center attorneys provide legal advocacy for the civil rights and human dignity of people with mental disabilities. Please note that the Bazelon Center is not able to handle individual requests for information or assistance. The Center's website does provide links to other advocacy resources that can offer assistance to persons with mental or developmental disabilities.

The Bazelon Center can be contacted at: Bazelon Center, 1101 15th Street NW, Washington, DC 20005, Phone: 202.467.5730, Web: www.bazelon.org.

National Association For Rights Protection And Advocacy

(NARPA). NARPA claims to be the only independent advocacy organization in the United States. Formed in 1980, NARPA is dedicated to promoting policies and strategies that represent the preferred options of people who are labeled as mentally disabled. The central issues of concern to NARPA are the abolition of all forced treatment laws, opposition to electroconvulsive therapy, and the enhancement of community services.

NARPA can be contacted at: NARPA, 587 Marshall, St. Paul, MN 55102, Phone: 612.224.7761, Web: www.connix.com/~narpa.

Finding Other Resources

The advocacy groups described above may not meet the unique needs of an individual consumer or professional. Many other advocacy groups exist, including the following: National Depressive and Manic Depressive Association; MADNESS; National Alliance for Research on Schizophrenia and Depression; Black Mental Health Alliance; Anxiety Disorders Association of America; AIM-Awareness; ACT-MAD; MadNation; The Support Coalition; Shocked; Families, USA; Public Citizen Health Research Group; and Psychiatric Survivors Advocacy/Liberation Movement. The following resources can be used to find these and other advocacy groups:

The National Mental Health Services Knowledge Exchange Network (KEN). KEN provides information about mental health through toll-free telephone services, an electronic bulletin board, and publications. KEN was developed for users of mental health services and their families, the general public, policy makers, service providers, and the media. KEN is a national one-stop source of information and resources on prevention, treatment, and rehabilitation services for mental illness.

KEN can be contacted at: KEN, P.O. Box 42490, Washington, DC 20015, Phone: 800.769.CMHS (weekdays from 8:30 a.m. to 5 p.m. EST), Fax: 301.984.8796, TDD: 301.443.9006, Web: www.mentalhealth.org.

National Institute of Mental Health (NIMH). NIMH advocacy work is done through educating the public on various mental and brain disorders through publications and nationwide prevention education programs. NIMH offers the public a number of informative materials on mental health topics. The Institute also offers toll-free information lines for specific disorders.

NIMH can be contacted at: NIMH, 5600 Fishers Lane, Room 7C-02, MSC 8030, Bethesda, MD 20892-8030, Phone:

301.443.4536, Web: www.nimh.nih.gov.

Self Help Clearinghouse. A resource for national and local self-help groups. The clearinghouse publishes a guide to self-help groups and operates a toll-free referral number: 800.FOR.MASH.

National Mental Health Consumer's Self-Help Clearinghouse. Another resource offering a toll-free information and referral line: 800.553.4539. This resource can also be accessed by writing: 1211 Chestnut Street, Suite 1000, Philadelphia, PA 19107.

Internet. Browse the web for the web sites of particular advocacy groups or those offering links to mental health web sites. The following web sites may be particularly helpful:

- www.mhsource.com
- www.handsnet.org (NAPAS)
- www.qeeg.npi.ucla.edu/advocacy
- www.klinks.com/generalinfo
- www.radix.net/ccd (Consortium for Citizens with Disabilities)
- member.aol.com/jimhofw/links.htm (Mental Health Web Sites)
- www.compeer.org
- www.protectionandadvocacy.com/odis.htm (Links to disability-related organizations)
- www.naotd.org/advocacy.htm (Links to advocacy web sites)

Furthermore, using the following key words will help counselors to find additional information on advocacy groups on the Internet: "mental health advocacy," "protection and advocacy," "support and advocacy," and, by typing in a particular topic, such as "depression."

Additional Resources

Encyclopedia of Associations. A reference guide to approximately 23,000 national and international organizations. Maurer, Christine & Sheets, Tara E. (1982). Encyclopedia of associations: An association unlimited reference. New York: Gale.

National Directory of Mental Health Advocacy Programs. Lists over 400 mental health rights protection and advocacy programs, including legal organizations, ex-patient groups, parents and

family groups, mental health associations, and patients' rights programs operating within departments of mental health. Greenberg, P., Freddolino, P. & Lecklitener, G. (1982). National directory of mental health advocacy programs. Los Angeles: Human Interaction Research Institute.

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